



Disability disaggregated data

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Acknowledgement

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Purpose, audience and objectives

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| Purpose | This guide looks at disability data disaggregation and also offers some guidance on how to monitor the quality of participation of young people with disabilities in programmes. By highlighting the purpose and importance of disability data disaggregation and monitoring participation, it aims to strengthen the availability, quality, and utilisation of disability data for evidence-based decision-making, policy formulation, and advocacy. |
| Audience | It is one of a series of short guides developed by Sightsavers, within Futuremakers by Standard Chartered , and specifically written with Youth Business International programme partners in mind. While advice included in the document is more targeted towards YBI's youth entrepreneurship programme, we have tried to make these relevant to all Futuremakers projects. |
| Objectives | <ol style="list-style-type: none">1. To build greater disability confidence of the reader and how partners can better include youth with disabilities in their Futuremakers projects.2. To give specific examples, advice and simple steps on how to adapt projects to be more inclusive of youth with disabilities. |

Context

Disability statistics and data disaggregated by disability can provide important insights about the extent to which persons with disabilities are being included in society. They can also provide a useful evidence base to inform the development of disability-inclusive policies and programmes. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the 2030 Agenda have created a legal and policy push for better data on persons with disabilities.¹ As noted in other guides in this series, at a programme level it is important to consider the intersectionality of discrimination. For instance, the experiences of people with disabilities in programmes will not only be informed by their impairment but also by other elements such as gender, age, education, etc. As such, it is important to understand that people with disabilities are not a homogenous group during data collection. People with different impairments will experience different barriers and challenges.

¹ **Disability Data Advocacy Toolkit, CBM, IDA, 2020**

Disability data disaggregation

Disability data disaggregation refers to the process of collecting and analysing data specifically relating to disability, allowing for a deeper understanding of the challenges faced by this diverse population. Sightsavers' programmes recommend using either the Washington Group Questions or Impairment data, where participants self-identify whether they have a disability and which impairment group they identify with, to collect disability data.

A practical example of this is reflected in Sightsavers' economic empowerment programme where disability data is disaggregated by type of impairment. Programme participants self-identify and select their impairment type from a list of available impairment options. It's recommended that the list of impairments is used in instances where population-level impairment data is available at a country level to ensure the data will be comparable.

Disability data collected in Sightsavers' economic empowerment programme is stored in a participant database, which allows for tracking the progress of each participant, having a better understanding of individuals' barriers to equal participation; and analysing by impairment group (as well as other characteristics like gender, age, education level, or any combination of these). This is important for understanding who is being excluded and identifying what needs to change or be adapted in the structure or delivery of the programme. Within this context, anonymising data is an absolute imperative. Personally identifiable data (name, address, email, telephone number) must be locally secured and never shared in compliance with both local & International (GDPR) data protection law.

Approaches for collecting disability data

Irrespective of the approach used to collect disability data, consent must first be collected from all individuals.

Impairment data

Participants self-identify whether they have a disability and which impairment group they identify with. This should always be reviewed for contextual appropriateness before using in a project. The list of impairments is recommended to be used in instances where population-level impairment data is available. If the suggested list does not correspond to country-level data, it should be reviewed to agree whether or how to adjust the impairment list for the project.

Washington Group Question sets

The use of the Washington Group (WG) Questions are targeted questions on individual functioning intended to provide a quick and low-cost way to collect data, which allows disaggregation by disability status.

- **Washington Group Short Set**
- **Washington Group Extended Set**

Monitoring participation

Monitoring participation helps assess the inclusion and active involvement of persons with disabilities across various domains and it is crucial for upholding the rights of individuals with disabilities. By tracking the representation of individuals with disabilities, it enables the identification of barriers that hinder their full and equal participation in society and areas for improvement. Monitoring participation helps ensure that efforts towards inclusion are measurable, accountable, and responsive to the needs of individuals with disabilities. Moreover, monitoring participation supports the implementation of international frameworks such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Strategies to monitoring participation

- **Data collection:** collect demographic data, including information about disabilities, to establish a baseline understanding of the characteristics of persons with disabilities participating in the programme
- **Tracking enrolment:** monitor the number of persons with disabilities who enrol in the programme. This helps assess the reach and accessibility of the programme to the target population
- **Attendance and engagement:** track the attendance and active engagement of participants with disabilities. This includes monitoring their participation in activities, events, or sessions related to the programme
- **Progress tracking:** monitor the progress of participants with disabilities over time. This can involve tracking their achievements, milestones, or completion of programme-related tasks or objectives
- **Feedback and surveys:** collect feedback from participants with disabilities to understand their experiences, challenges, and suggestions for improvement. Surveys, interviews, or focus groups can provide valuable insights into their perspectives
- **Inclusion and accessibility:** assess the level of inclusion and accessibility within the programme. This includes evaluating the availability and utilisation of accommodations, such as assistive technologies, accessible materials, or communication support, to ensure the active participation of persons with disabilities

Now that I know, what do I need to do?

There are some simple steps you may start taking at an organisational level to help you start collecting disability disaggregated data and critically analyse what the data tells you about who is participating in your programme, the quality of their participation and who isn't participating.

- **Advocate for organisational commitment and develop a strategy to improve disability data collection.** You may for example update your participant sheet template by inserting a column to track the type of disabilities of participants. This tracker/sign-in sheet will help your team monitor the participation of diverse groups of persons with disabilities, and take appropriate measures to ensure meaningful participation of all impairment groups

- Gather qualitative information from people with disabilities as, without it, organisations cannot understand their experiences and what needs to be adapted to increase the inclusiveness of programmes, or design inclusive activities
- Train staff both in disability awareness and then in any data collection tools being used
- Share the disability data that your organisation collects as one way of learning and improving

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